

# Hope for Women in Recovery Understanding and Addressing the Impact of Prenatal Alcohol Exposure

Phoenix, Arizona • June 29-30, 2004



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SAMHSA  
Fetal Alcohol Spectrum Disorders  
Center for Excellence

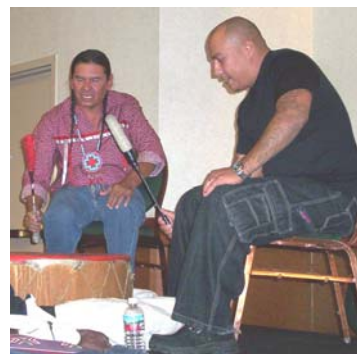
## Introduction

Nearly 40,000 babies are born each year with a range of birth defects known as fetal alcohol spectrum disorders (FASD). To address the problems related to FASD, Congress created the FASD Center for Excellence as part of the Children's Health Act of 2000. The Center is operated by the Substance Abuse and Mental Health Services Administration (SAMHSA). The Center has six legislative mandates, one of which is to develop innovative ways to prevent alcohol abuse among women in their childbearing years.

In 2003, as part of its efforts to address the legislative mandate regarding prevention of alcohol abuse, the FASD Center convened the first-ever summit for women in recovery from alcohol abuse. The summit was so successful that the Center followed up with a second summit in Phoenix, Arizona, June 29-30, 2004. The National Organization on Fetal Alcohol Syndrome (NOFAS) hosted the meeting.

The first day was designed to educate women of childbearing age who were in substance abuse treatment and treatment center staff about the effects of prenatal alcohol exposure and the needs of children with FASD. At the end of the day, a town hall meeting was held, where women could share their stories about how alcohol affected them with policymakers and government staff. The second day involved policymakers from the Indian Health Service, the State of Arizona, and Indian nations within the State. They came together to learn about FASD and how it affected individuals within their State.

About 200 people attended the first day of the summit, including women from Arizona treatment centers, along with treatment center counselors and staff from NOFAS and the FASD Center. Participants were primarily Native American, and the meeting incorporated aspects of Native culture such as a spiritual opening and closing and drumming. About 100 people attended the second day, including State policymakers and government officials.



**Tuesday June 29, 2004**

### Spiritual Opening Ceremony

**Timothy Terry, Jr.,** Counselor, Gila River Indian Community

Mr. Terry opened with remarks about his mother, who raised him by herself. He noted how great the responsibility of motherhood is. Parents cannot make up for past wrongs done to their children, but they can make today better for them and make a better future. It is not enough to apologize to your children. You must also act to make things better. After these remarks, Mr. Terry performed a song of prayer and a traditional ceremony that included an offering of salt to participants and their children.

## Summit Overview and Welcome

**Callie Gass**, Project Director, SAMHSA FASD Center for Excellence

Ms. Gass explained the purpose of the meeting and the history leading up to this event. This was the second meeting for women in recovery. The first was held in Baltimore. The first meeting was so successful that the FASD Center worked with NOFAS to convene a second meeting. The goal is to have a series of meetings like this at different locations throughout the country.

Ms. Gass stated that the meeting would give participants a chance to talk about their experiences and those of their children. They could also talk to wonderful mothers who have overcome adversity and entered recovery. In addition, they would learn how alcohol affects women and their children. She then described the events planned for the day and reviewed logistics.

## Alcohol and Women: What You Need to Know

**Candace Shelton, MS, CSAC**, FASD Specialist, Johnson, Bassin and Shaw

Ms. Shelton is a psychotherapist and certified substance abuse counselor who has specialized in FASD. She presented information on how alcohol and alcoholism affect women. She also described her own experience in recovery.

Ms. Shelton noted that most treatment models for alcoholism in use today were developed for male clients. Although fewer women than men drink, an enormous number of women have alcohol-related disorders. One-third of people in the United States who abuse or are dependent on alcohol are women. Thus, nearly 5 million women have alcohol-related disorders.

Among women who drink, younger women (age 18 to 34) report higher rates of alcohol-related problems than older women. Problems include unsafe behaviors, abuse, and rape. However, the incidence of alcohol dependence is greatest among middle-aged women (age 35 to 49).

Women are less likely to drink as they get older, but women who start drinking later in life are more likely to become dependent on alcohol. They seem to become dependent quicker than women who begin drinking at younger ages. Women who are single, divorced, or separated are more likely to drink heavily and have alcohol-related problems than married or widowed women. Also, research shows that women who were sexually abused as children are more than three times as likely to have alcohol-related problems.

Ms. Shelton also stated that depression is a very common trigger for women who drink, and women in treatment need to be able to talk about the anger that causes their depression. Women who are depressed may drink more. Because alcohol is a depressant, it can worsen their depression. Recent data also show that a greater number of women today are drinking to relieve stress, which may be because women's lives are becoming more stressful.

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Women also react differently to alcohol than men. They metabolize alcohol very differently, because they have lower total body water content than men. Since women have less body water, the alcohol in their system is less diluted. They reach a higher concentration of alcohol in their blood than men who drink the same amount. Women also have less activity of the ADH enzyme, which is used to metabolize alcohol in the stomach before it reaches the bloodstream. Finally, fluctuations in a woman's hormones during the menstrual cycle may affect alcohol metabolism.

Women who are chronic alcoholics have a higher incidence of liver and brain damage than men with the same disorder. Women's brain cells seem to be killed at a greater rate by alcohol than men's. Thus, women who are alcohol dependent have a higher incidence of dementia. Because a greater percentage of alcohol consumed enters their bloodstream, they also have a higher rate of heart disease than men with alcohol disorders. Other significant problems for women related to alcohol use include breast cancer, violent victimization, and traffic accidents.

Ms. Shelton stated that 25 percent of clients in treatment for alcoholism are women. A major reason for women to seek treatment relates to their families. However, women face barriers related to money and the need to provide child care. For many women in recovery, safe housing, child care, financial assistance, and family integration are significant issues. A woman may do well in treatment but return to the same living situation they faced when drinking, thus making continued sobriety difficult. Many women have trouble finding the transitional housing they need after they leave treatment, especially housing that allows them to live with their children.

In addition to treatment issues, Ms. Shelton discussed the effect of genetics and family behavior patterns in perpetuating alcoholism. A person with an alcoholic parent is 40 percent more likely to have an alcohol-related disorder. If both parents have alcoholism, the risk is 80 percent.

In her own case, Ms. Shelton realized that she was like her mother, who had alcoholism, and sought treatment. In sobriety, she has focused on working with women and their children and especially with Native populations. She concluded by telling the audience that there never has to be another child born with an FASD if women stop drinking during pregnancy. She then read a poem on women.

### Owning Your Warrior

**Kathleen Tavenner Mitchell, MHS, LCADC, NOFAS Vice President and Spokesperson**

Ms. Mitchell has a child with fetal alcohol syndrome (FAS) and is in recovery from addiction. She thanked all the people involved in developing the meeting for their work and the participants for attending. She acknowledged one of NOFAS's cofounders, Gwen Packard, and explained the role of NOFAS:

- Serve as a resource and referral clearinghouse.
- Advocate for families affected by FASD.

- Develop curricula for medical and allied health professionals and students in those fields.
- Organize training workshops, seminars, and conferences for professional and lay audiences.
- Provide peer education and youth outreach.

Ms. Mitchell noted that a great deal has changed in the way FASD is understood and discussed since NOFAS was founded in the early 1990s. At that time many treatment providers believed that this was an issue that women could not handle while still in treatment. Today, we have a conference where women in treatment can learn about this topic and openly discuss it.

Ms. Mitchell shared her beliefs and experiences with alcoholism. Alcoholism is a physical disease that appears as a mental disorder because it affects how we think and act. She talked about her daughter Karli, who was born with FAS, and about how substance abuse has affected her and her family.

Ms. Mitchell had an alcoholic father and two alcoholic grandfathers. Growing up, she never knew the real source of her family's problems. She begins her story of recovery by talking about her childhood because that is the root of her addiction.

One way being raised by an alcoholic father affected Ms. Mitchell was that she tended to seek partners who had problems with addiction and acted abusively. Because of his alcoholism, her father abused her mother, and she had to be a caretaker of her mother and siblings. When her father got sober years later, she discovered that he was a sensitive and sweet man who grew up fearing his own alcoholic father and whose behavior was changed by alcohol.



In school Ms. Mitchell found that she had a talent for drinking but problems in many other areas. In high school she began to experiment with drugs, and heroin became her drug of choice. When she became pregnant in high school, she gave up illicit drugs because she wanted a healthy baby. She continued to drink wine because she thought it would help the baby.

Ms. Mitchell was also drinking when her second child, Karli, was born. While Karli had FAS, it took years to identify the problem. Before that, she was misdiagnosed with cerebral palsy. Ms. Mitchell had another child who was born dead and one who died of sudden infant death syndrome. In both cases she believes her alcohol use played a part in their deaths.

Throughout her pregnancies, Ms. Mitchell believed that because she was only drinking and not using other drugs she was doing well and would have healthy children. However, her substance abuse was a major problem that affected her and her children. She used to believe that she could not enter a treatment program because her children needed her and she wanted to be there for them. But when she was using she was not really there for them and her continued use hurt them as well as her.

Ms. Mitchell noted that recovery from addictive diseases is possible for women. Recovery must address issues that are pertinent to women. These include dealing with codependency, developing new communication skills, changing belief systems, and discovering one's spirituality.

### Understanding FAS: A Brain Based Disorder

**Ardyce Turner**, Children's Services Specialist, State of Alaska Office of Children's Services

Ms. Turner has been working on the issue of FAS on a volunteer and then professional level since the 1980s. She began by introducing herself and explaining who her parents and grandparents were. Then she talked about her personal experiences with substance abuse and FASD.

Ms. Turner is now in recovery but was still drinking when she was pregnant with her son. Her binge drinking got worse toward the end of her pregnancy. At one point she had an accident that she feared would harm her unborn child. When he was born she was told that he was not affected by the incident.

It was not until her son was 5 years old that Ms. Turner was informed about FAS by a task force that had been started to educate her community. Sometime after that she began to notice that her son had conduct problems in school, in spite of doing well as a student. He was later diagnosed with attention deficit disorder and a conduct disorder that were likely effects of her drinking while pregnant. No one recognized how his behavior, such as biting, and poor memory were related to an underlying problem of FAS for quite a while. He had a number of behavior problems that followed him into adulthood, although the situation has improved.

Ms. Turner learned that even though she did not drink heavily early in her pregnancy, her drinking during the third trimester affected her son's cognitive and planning abilities. These effects occurred because rapid development of the brain takes place during the third trimester. Drinking in the first trimester is associated with changes in physical development associated with FAS. Since a child's brain develops from conception, drinking at any stage of pregnancy can affect the brain.

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Alcohol is a teratogen. It disrupts fetal development and causes birth defects. These defects may be physically apparent or may affect the central nervous system without any physical signs. The effects are permanent, unlike some of the fetal effects caused by other drugs. Whenever a mother drinks during pregnancy, the child is affected. The degree to which it is affected depends on the mother's and the baby's genetic makeup and the amount the mother drinks.

Children with FASD are affected by a brain disorder that causes problems in their ability to communicate and understand the world around them. Ms. Turner showed slides of how alcohol affects a developing brain in the fetus; some areas of the brain are likely to be more



affected than others. These effects on the central nervous system may be difficult to detect at birth. Other signs of FAS are easier to diagnose (e.g., epicanthal folds, minor ear abnormalities, a flat midface, short nose, and low nasal bridge).

The cognitive effects of FASD may include difficulties processing information, integrating new information, remembering things, and expressing oneself. Difficulties with abstract reasoning are common. For example, Ms. Turner's son takes everything literally and often misunderstands metaphors. Other mental difficulties may include:

- Impaired ability to generalize
- Inability to understand issues related to time
- Problems with judgment
- Difficulties with socialization and acting independently

Persons with FASD may also have problems with eating and sleeping patterns.

Ms. Turner concluded by noting that children with FASD are protected by the Americans With Disabilities Act and other legislation. She stressed the importance of supporting children with FASD as much as possible.

### **Beyond the Doom and Gloom**

**Suzanne L.B. Kuerschner, MEd, S.P.I.R.I.T.S.**

Ms. Kuerschner is a child development specialist who specializes in FAS and related neurodevelopmental disorders. She works primarily with Native American communities. Ms. Kuerschner introduced herself and thanked the audience for being present and showing courage and hope in getting sober. Her talk focused on "Knowledge and Prevention for Healthy Families and Futures."

Ms. Kuerschner began by noting that more prevention materials, program curricula, and trainings on FASD interventions come from Indian communities than for any other ethnic group. This shows that tribal and county services working together can develop powerful and useful prevention and intervention models.

Ms. Kuerschner cited a Native American prophecy that a time would come when some among us would look different and with those differences they would change the people. She noted that this prophecy could be understood as looking at the role of children with FAS in the community. When people hold a baby with FAS they can see it as beautiful and recognize it as a gift.

Ms. Kuerschner then discussed how Native American beliefs, values, and practices are useful in raising children with FASD. She noted that traditional practices may be more effective than those suggested by Western medicine. For example, the traditional cradleboard is very useful for these children because it keeps them still and therefore comforted. The cradleboard serves as an essential first neurologic intervention with children who have FASD.

Other cultural beliefs and practices such as having respect for elders and the importance of showing people when they are doing something right are useful with children with FASD. However, children with FASD who learn using traditional ways may face certain difficulties. For example in Native American cultures children may be taught to learn by observing others but this can prove difficult for children with FASD.

Ms. Kuerschner explained that as she uses the term, FAS is not at one end of a spectrum with related conditions caused by exposure to alcohol at the other end. FAS itself is a continuum. The disorder characterized as FAS reflects a set of features that is a consequence of alcohol use in the first trimester. Use during the next 6 months will also affect a child even though he or she does not have the physical or facial features associated with FAS. The child can still have cognitive and emotional problems.

Children with the cognitive effects of FASD often have difficulties processing information. They cannot understand, cannot remember, and cannot act upon it. These children will process information concretely and have difficulty generalizing from a single instance. If shown a street during the day and told not to cross it, they may not understand that they should avoid crossing at night when the street appears different. They may believe that all other streets are safe to cross without being specifically told otherwise.

Children with FASD may also have difficulties transitioning between activities, solving problems, and predicting the outcomes of their actions. Their senses can also become overloaded by sensations and therefore they may find it difficult to focus on one thing. Ms. Kuerschner stressed that children with FASD are not destined to do things wrong. They need to be instructed in a way that communicates to them and takes into consideration their cognitive limitations. They should be shown things and not lectured to. Role playing is more helpful in demonstrating how to respond to situations. They also may need to be shown the same thing repeatedly in different contexts.

Children with FASD are not destined to do things wrong. They need to be instructed in a way that communicates to them.

In addition, children with FASD are often extremely social. This behavior can get them into trouble as they grow older. What appears cuddly and friendly in youth seems clinging in adults. Because they may be gullible, people with FASD may be confused or used by others. They can also become model members of a community if the people who interact with them have good intentions.

Ms. Kuerschner explained how the cognitive and emotional problems associated with FASD can lead to secondary problems if children are not taught and treated properly. Feelings of failure at tasks for which they are not adequately prepared may lead to depression, other mental health problems, and substance abuse. Frustration caused by communication difficulties can lead to temper tantrums, oppositional defiant disorder, and involvement in the criminal justice system.



Difficulties in processing, memory, and cognition may lead to failure in school and in the workplace. A need for social and physical reinforcement can result in inappropriate sexual behaviors. Like anyone else, people with FASD may retreat or act out when they have problems interacting with the world around them. Many of these problems can be avoided if their caregivers take the proper steps.

Ms. Kuerschner outlined some of the intervention strategies that seem to work for children and adults with FASD:

- Observe the individual's behavior and way of doing things to identify strengths and skills. Figure out how they can be applied to address the particular needs of a situation.
- Understand that behavior is a form of communication and try to understand the message behind the behavior.
- Remember to show correct behavior rather than just describing it.
- Understand the need for structure and a calm environment.
- Understand the need for consistency on the part of the caregiver.
- Create a "map" of positive behavior that shows how things should be done and labels correct behavior as "right."
- Understand the effects of a lack of abstract reasoning and a tendency to process information only concretely.
- Beware of placing ceilings on expectations and avoid saying that they'll never be able to do something. People with FASD can often exceed expectations.
- Help them to generalize behaviors from specific incidences.

By using techniques such as these, caregivers can help build resilience and provide people with FASD with a life that reflects their culture and community.

To illustrate her point, Ms. Kuerschner showed slides of her family. She talked about how her people's culture is reflected in her family life and how that culture helps make the family stronger and healthier. She noted that prevention and intervention reinforce one another and that an intervention for one generation acts as a prevention measure for the next.

When they drink, women do not intend to harm their unborn children. Mothers love their children, and fathers want healthy families. Women drink to dull feelings of failure, medicate the pain of the past, and decrease the overstimulation of their environment. Ms. Kuerschner concluded by noting that mothers alone are not responsible for the welfare of their children. Everyone in the community is responsible for the next seven generations.

### **Circle of Hope: Warrior Moms Unite**

**Moderator: Kathleen Mitchell**

**Panel Members: Julie Gelo, Diane Malbin, Pat Hoagland, Felicia Pablo, Ardyce Turner, Ruth Ortega**

Kathleen Mitchell chaired this panel discussion for mothers who had raised or were raising children with FASD. She introduced the participants and asked them to tell their stories. She

reminded participants that they would have an opportunity to share their experiences and concerns with policymakers by testifying at the afternoon town hall meeting.

### **Julie Gelo**

Ms. Gelo talked about how alcohol affected her. She grew up with an alcoholic father and began drinking regularly by the age of 13. She first got in contact with the recovery community through Al-Anon, which she attended because of her then-husband's drinking. People there suggested that she look at her own drinking and she realized it was becoming very similar to her father's. After that realization she went into treatment and got sober.



In recovery Ms. Gelo has become a foster mother to 26 children who have FASD and the legal mother to 13. She currently has seven foster children living with her, all of whom are diagnosed with an FASD. It was not until after she became a foster parent to a child with an FASD that she began to see that her birth children had some of the same problems. When Ms. Gelo's daughter was 25 and pregnant with her first child she was diagnosed with an FASD. Ms. Gelo felt more guilt and shame than she ever had. Her daughter forgave Ms. Gelo and understood that she did not drink in order to harm her.

### **Pat Hoagland**

Ms. Hoagland began her story by stating that she had no idea that when she got sober she would have to deal with FASD. She also grew up in a home with alcoholism and felt confused by her family's behavior. She felt left out until she had her first drink. Her first husband seemed to have a far worse problem with alcohol than she. For a long time this kept her from seeing the extent of her own problem. However, her drinking and prescription drug abuse affected her life and the lives of others, causing family problems and interfering with her ability to work.

During this time Ms. Hoagland worked as a special education teacher and she first learned about FASD when a child with FAS entered her class. Her oldest son had problems from the day he was born. When Ms. Hoagland talked with the mother of this child, she suggested that Ms. Hoagland's son might have an FASD as well. It was not until years later, however, that she understood that he had been affected. Her son later became addicted to crack cocaine and was arrested repeatedly. He was also diagnosed with bipolar disorder. He is now serving a 30-year sentence in a Federal prison but adapts well to the highly structured environment of prison life.

Ms. Hoagland concluded by stating that when you have a child with an FASD you lose many of the dreams you have for that child and the things you hope he or she will accomplish. She told the audience to make sure their children are diagnosed early and that if they have FASD they receive the help they need.

### **Marceil Ten Eyck**

Ms. Ten Eyck grew up in a family with alcoholism, but in her family people identified her mother as the one with the serious problem. She did not want to be like her mother and did not start drinking until she was 21. Still, she ended up in a hospital with cirrhosis.

When she finally entered treatment and got sober, her husband divorced her and took her children with him. Slowly she was able to get her children back. After 3 years of sobriety, she went back to school to become a substance abuse treatment counselor and learned about FAS.

Because her children lacked the facial features of FAS, she thought they were fine. Later, when her daughter was evaluated for learning disabilities, she was diagnosed with FAS. Now she is doing well and has exceeded academic expectations. In fact, her daughter was relieved to learn the cause of her academic difficulties. Ms. Ten Eyck also has an older daughter and a stepdaughter with fetal alcohol effects, although they do not have an FAS diagnosis.

### **Ardyce Turner**

Ms. Turner began by noting the importance of a sober and caring partner in raising a healthy child. She said that she lives a very traditional life in her community and that community life is very structured. For her son, who has an FASD, this structure helps him to adapt in spite of his memory and other cognitive problems. For example, her son is a successful hunter, which is valued in their community. He has learned to build on such strengths. She stressed the importance of focusing on strengths for children with FASD. Ms. Turner concluded that healthy generations are possible and prevention can work if everyone in the audience will share the knowledge they gained here with the rest of their communities.

## Questions and Answers

Ms. Mitchell briefly summarized some of the common ground of presenters, noting that it took some time for panel members to finally understand what was going on with their children. She stated that children with FASD are not being assessed or people who do not really know about FASD are doing the assessments. After these remarks, panel members fielded questions from the audience. The questions and the panel members' responses are summarized below:

- Q: Does alcohol use by men affect their sperm and might that affect a child?  
A: While there has been very little research on the subject, alcohol does seem to decrease the volume and mobility of sperm. The main reason for men to stay sober, however, is to support their partners in pregnancy. It is easier for a woman to avoid alcohol use during pregnancy if her partner does not drink.
- Q: How did you learn to cope with learning that your child was affected by an FASD as a result of your own behavior?  
A: The first respondent said that she used 12-Step support groups and the support of friends and coworkers. The second said that spirituality and the support of a higher power were very important to her. The third respondent said it was important to choose today to see things in a positive light rather than a negative one. She looked on her children with FASD as a gift.
- Q: Do these disorders affect African-Americans in the same way as people of other races?  
A: Yes, and materials teaching about FASD have been prepared for an African-American audience in Washington, DC.
- Q: Were panel members also smoking during their pregnancies?  
A: Some were, and while nicotine can cause some problems in pregnancies it does not cause permanent damage like alcohol. None of the other common drugs of abuse do the same type of damage as alcohol.
- Q: The questioner noted that her children were born with midwives and not doctors in attendance. They look fine but have problems in school. She asked how to get her children diagnosed.  
A: Panel members encouraged her to find someone who knows about FASD to perform the diagnoses.
- Q: Does it matter if a pregnant woman is only drinking beer and not hard alcohol?  
A: It does not matter – beer still contains alcohol.

Ms. Mitchell concluded the discussion by telling audience members that if they wished to tell their own stories to policymakers in Arizona they could do so at the town hall meeting later in the afternoon. Those who wished to testify could attend a meeting beforehand to help them prepare. She then thanked all participants and the audience. Juanita Homer finished this

portion of the session with a prayer. Information on the testimony provided at the town hall meeting is available in a [separate report](#).

**Wednesday, June 30, 2004**

### **Welcome and Spiritual Opening**

**Larry Foster**, Adoptive Parent of a Child With FAS

Mr. Foster opened the day's session with a prayer and blessings. He then talked briefly about his adopted son who was born with FAS to an alcoholic mother in Gallup, New Mexico. At that time alcohol was cheap and easily available and the policies that allowed that harmed Native Americans. He noted in the 19th century, one of his ancestors took into his clan orphans and children with disabilities. He followed the example of this ancestor in adopting his son. Today, like then, the Navajo suffered from discrimination.

Mr. Foster also talked about the importance of women in Navajo culture and his own life. He said that today he wanted to honor all the women who were present: women in recovery, women as mothers and grandmothers, women as policymakers, and women in leadership. He concluded by expressing hope that all tribal members affected by alcohol begin a healing process.

### **An Introduction to the SAMHSA FASD Center for Excellence**

**Callie Gass**, Project Director

Ms. Gass introduced herself and explained the purpose of the FASD Center. She summarized day 1 of the meeting, which provided information about FASD to women in treatment and their counselors.

The FASD Center was created by congressional mandate (Children's Health Act of 2000) and was given five tasks, three of which were important for today's sessions. These are

1. To identify which States had comprehensive systems of prevention and intervention for FASD, which unfortunately turned out to be none.
2. To help States identify what they need to build those systems and assist them in doing so, which was the major intent of the day's meeting.
3. To develop innovative methods of prevention and education that will help women avoid alcohol during pregnancy, which was the primary task of the previous day's meeting.

Ms. Gass expressed hope that today's meeting would help policymakers better understand the science, effects on families, and costs of FASD. She hoped that would gain insight into what can be done in Arizona to address this problem. The goal at the end of the day was to have a core group of people who could move this issue forward in the State.

The FASD Center has a training team that can provide technical assistance to providers in the State and a Web site ([fascenter.samhsa.gov](http://fascenter.samhsa.gov)) that provides a number of information resources, including educational materials that can be reproduced.

## FASD: Effects on Individuals and Communities

**Kathleen Mitchell, LCADC, NOFAS Vice President and Spokesperson**

Ms. Mitchell talked briefly about the previous day's events and her own experiences with FASD before discussing how FASD affects individuals. She noted that today's meeting will inform audience members about both the effects of FASD in general and the specific situation in Arizona. She hoped participants would get a better idea of how the State can change policies and practices to prevent FASD and improve services for people with FASD and their families.

The mission of NOFAS is to "address alcohol use during pregnancy, the leading known preventable cause of mental retardation and birth defects." NOFAS is a nonprofit organization that works with the government to prevent FASD, intervene when FASD, and advocate for and support those affected by FASD. NOFAS gets calls from all over the world from mothers, families, doctors, and others. It also acts as a clearinghouse for information about FASD and can direct interested parties to materials developed by Federal agencies and private organizations.

NOFAS also does national trainings for a wide variety of audiences, from grade-school children to large professional conferences. It is also developing a curriculum for substance abuse treatment counselors and another curriculum for medical students. It has prepared campaign materials for a variety of different audiences.

Ms. Mitchell talked about her daughter Karli, who has FAS. When Ms. Mitchell was pregnant she thought alcohol consumption was o.k. and did not know its potential effects on her unborn daughter. When Karli was born no one recognized that she had FAS, and no one told her what to look for to determine if Karli had been affected. When her daughter was young, people said that she was willfully disobedient and later diagnosed her as having cerebral palsy.

Ms. Mitchell noted that maternal alcohol use is the leading known cause of preventable mental retardation and a leading cause of birth defects and learning disabilities. All the effects of prenatal alcohol exposure are lifelong. Ms. Mitchell stated that people may think that mothers who have children with FASD are horrible, but she had never met one who intentionally harmed her child. They drank because they lacked knowledge or access to proper treatment.

FASD represents a spectrum of diagnosable disorders:

- FAS is at one end of that spectrum and is a condition in which alcohol affects facial features, damages the brain and central nervous system, and retards growth.
- Partial fetal alcohol syndrome (PFAS) is a less severe version of FAS that involves only some of the effects of "full-blown" FAS.
- Alcohol-related neurodevelopmental disorder (ARND) is a diagnosis of central nervous system and brain damage caused by alcohol use without the characteristic facial features or growth retardation.



- Alcohol-related birth defects (ARBD) involve malformations of the skeletal system and major organs but not the neurologic effects associated with ARND and FAS.

Ms. Mitchell also stated that people are beginning to recognize that sudden infant death syndrome (SIDS) may be related to FASD. ARBD and ARND are both considered diagnoses of fetal alcohol effects (FAE).

Reviewing current data on FASD, Ms. Mitchell told the audience that 1 out of every 100 infants born in the United States has some degree of damage due to prenatal alcohol exposure. This represents 38,900 children born each year with alcohol-related effects and 7,780 who meet the criteria for an FAS diagnosis. This is greater than the 3,900 children born each year with Down syndrome, 1,244 with spina bifida, or 1,216 with muscular dystrophy. Yet these other disorders are better known by the general public.

The information on alcohol consumption by women of childbearing age in Arizona is particularly alarming. Between 1999 and 2002, Arizona had the greatest increase (136.7 percent) of any State in reported binge drinking among women 18 to 44. Binge drinking does seem to have pregnancy outcomes, as pregnant women who drink five or more drinks at a time are eight times as likely to have a child die of SIDS.

Alcohol is a teratogenic drug, meaning that it causes permanent damage to the fetus. Other drugs may increase the chance of a miscarriage (e.g., heroin) but do not have the long-term effects of alcohol. Ms. Mitchell showed a slide of two brains: one of a baby with severe FAS and one of a typical baby. The differences were striking.

Ms. Mitchell also reviewed the effects on central nervous system functioning most commonly seen in FASD. These include cognitive deficits or developmental delays, delays or deficits in motor functioning, attention and hyperactivity problems, social skill problems, and mental illness. Children with FASD may also have sensory problems, language problems, and memory difficulties.

Typical parenting and teaching methods are unlikely to work for children with FASD. They need specialized care. To develop strategies for care and treatment, it helps to understand what parts of a child's brain are affected by alcohol. It also helps providers to understand the secondary effects of FASD in order to prevent them.

Ms. Mitchell introduced research by Ann Streissuth at the University of Washington that examined 415 people with FASD, ages 6 to 61. Many of these individuals had developed secondary disabilities as a result of their FASD. They had high rates of:

- Mental health problems (90 percent)
- Disruptive experiences in school (60 percent)
- Legal trouble (60 percent)
- Confinement (50 percent)

- Inappropriate sexual behavior (50 percent)
- Substance abuse problems (30 percent)
- Employment problems (80 percent)
- Need for dependent living (80 percent)

Streissguth also found that certain things decreased the risk of secondary disabilities, such as:

- Having a stable nurturing home environment for over 72 percent of their lives
- Being diagnosed with an FASD before the age of 6
- Never having experienced violence against oneself
- Remaining in a given living situation for an average of more than 2.8 years
- Experiencing a good quality home from age 6 to age 12
- Having applied for and been found eligible for Developmental Disabilities Services
- Having a diagnosis of FAS rather than FAE
- Having one's basic needs met at least 13 percent of the time

As a result of FASD, many social services have an increased burden. FASD affects the health care, education, justice, housing, mental health, substance abuse treatment, disability, and public assistance systems. If it goes untreated the financial burden for those systems increases.

Ms. Mitchell said that the first step in preventing secondary disabilities is to correctly diagnose the disorder. Too often FASD goes undiagnosed. After diagnosis, attention must be paid to educating parents and teachers so that they can understand characteristics of FASD. Parents often dramatically change how they respond to their child's behavior and experience a greater ability to cope with FASD-related problems when they understand the cause.

With better education about FASD, teachers and parents begin to view children as having organic brain damage and no longer label them "bad kids." Instead, families and caregivers can focus on these children's strengths. They are typically friendly, helpful, likable, pure of heart, and not malicious. They have a strong desire to be liked by others and are good with younger children, older adults, and animals. Ms. Mitchell's own daughter, for example, works with adults with mental retardation.

In addition to improving treatment and care for people with FASD, more effort needs to be made to prevent these disorders. The primary prevention method is to provide reproductive health planning so that women who are drinking will not get pregnant unintentionally and women who plan to get pregnant can stop drinking. Secondary prevention occurs in assessing FASD in children whose mothers are in substance abuse treatment, educating physicians and other providers to screen and assess FASD, advocating for families raising children with FASD, and creating support groups and networks who can help empower women who have children with FASD.

## Developing an FASD State System

**Suzanne L. B. Kuerschner, M.Ed., S.P.I.R.I.T.S.**

Ms. Kuerschner introduced the idea of circles of collaborative care. She noted that everyone wants to encircle his or her family with compassion and care, which in turn leads to hope. This is a task for the whole family and for the community. When a family cares for a child with an FASD, the whole family is affected. Providers need to understand the problems the whole family faces in dealing with this issue as well as the strengths they bring.

Parents and teachers need to be taught to cognitively retailor strategies for teaching and parenting to help children with FASD learn. For example, one cannot simply rely on expressive language or lecturing to teach people with FASD. They may fail to understand even simple concepts unless other teaching strategies are used.

Ms. Kuerschner gave an example of a man who was over 70 years old and in substance abuse treatment for the seventh time. He was finally diagnosed with an FASD, after which providers could tailor treatment to his needs. He has been sober for 12 years.



Ms. Kuerschner noted that even something that may appear insignificant, such as the architectural plan of a building, can affect learning for children with FASD. For example, straight hallways encourage children to run and high levels of environmental noise can distract them. They also rely to a much greater degree on visual learning and need to see things demonstrated. In training individuals to understand how persons with FASD learn, Ms. Kuerschner may ask them to veil their faces so that they can see how important the visual element is for their own learning.

Ms. Kuerschner also talked about the importance of creating and facilitating collaborative systems and provider prevention systems to address FASD. Through such systems, providers can work to remove the stigma from services for people with FASD. They can also integrate provider networks with families and community members to improve services for persons with FASD and identify and list all the community-specific resources available.

Providers cannot expect children with FASD to have all their needs met by schools or other social programs. Therefore, any system designed to assist people with FASD and prevent FASD in future generations needs to involve families. Unless they are educated about FASD, families may negatively influence individuals. For example, parents may tell children that it is o.k. to drink a little during pregnancy. With education they can have an enormous positive effect. In providing family education it is important to meet families “where they are” and understand the cultural background of a family to tailor interventions to their needs.

Systems that address FASD also need to be flexible so that they can shape prevention services to reflect the context of the strengths and needs of a specific community. The community forms the environment in which both the child and the family reside. One way to do this is to develop a community task force for FASD prevention and treatment that includes service providers and community members. Task forces should involve a wide range of participants, including:

- Families affected by FASD
- Educators
- Behavioral health providers
- Public health providers
- Students
- Elders and community leaders
- Representatives from criminal justice, child welfare, and vocational training

Ultimately, task forces can lead to the development of diagnostic teams, which can involve community members and make significant changes in attitudes. Ms. Kuerschner mentioned the Fort Hall diagnostic team, which has been running for 2 years. Community members now come willingly to the program for help even though they were initially resistant to its presence.

Once a task force has been formed, it can undertake site-based training for the community. Such training should take into account that prevention and intervention are reciprocal activities, early intervention is extremely important, and a multidisciplinary approach works best. The task force needs to develop specific materials for prevention and early intervention based on the community. They should also identify appropriate community-based sites for these activities (e.g., health care clinics, schools, early childhood centers) and prepare appropriate referral procedures and policies.

Ms. Kuerschner then presented some guiding principles for a collaborative system of care for families. She noted that such systems are most successful when they:

- Model multidisciplinary trust and promote a climate conducive to positive relationships with families.
- Ensure that providers are educated about child development, the consequences of organic brain damage, and the stresses and problems that families face in dealing with FASD.
- Model positive cooperative relationships among administration and staff.
- Link and coordinate points of entry into a continuum of services.
- Develop policies and procedures that are cooperative and based on community assessments of strengths, needs, and resources.
- Ensure that services do not depend solely on outside funding but will be supported by community resources.
- Understand that sustainable behavior change is the result of both skill acquisition and habituation over time.
- Ensure that families feel like equal partners in service relationships so that service delivery is not something that is “done to” them but rather something designed with them.

- Deliver services in a way that reflects a family focus and use forms and delivery strategies that respect this focus, as well as conforming to confidentiality laws.
- Develop demonstration models for replication that describe program content rather than prescribe protocols.

Ms. Kuerschner again noted the importance of culturally competent services. She then showed examples of a vision statement, mission statement, and values statement that took into account cultural and community values:

- *Vision Statement:* To provide a collaborative consortium of social, emotional, educational, and vocational services that promotes holistic, integrated, and culturally congruent access to children and families.
- *Mission Statement:* To provide these social and educational services in a multidisciplinary, multiagency, and family context that facilitates functional use of the service menu and integrates access to and implementation of individually designed strategies for resilience and development.
- *Values Statement:* That prevention and intervention are reciprocal and that children and families can benefit from strategies that build on their identified strengths and facilitate easy geographic, cultural, and conceptual access to services that are integrated via an interagency site-based model.

Ms. Kuerschner concluded by showing samples of a memorandum of agreement form, service plan cover sheet, coordinated service plan form, and family release of information form.

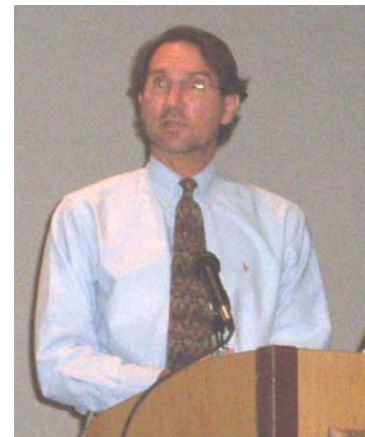
### Economic Costs of FASD in Arizona

**Henrick Harwood**, Lewin Group

Callie Gass introduced Henrick Harwood, a senior health economist with the Lewin Group. She noted the importance of the work he does, which makes up some of the information most requested from the FASD Center. She stated that while the data he was going to present may not be necessary on a daily basis, it was very important for anyone doing advocacy work concerning FASD.

Mr. Harwood noted that across the United States, FAS cost about \$5.4 billion in 2003 and about \$100 million in Arizona. This amounts to a lifetime health care cost of \$860,000. To cover this cost, it would be necessary to invest \$300,000 today. The lifetime costs can be as high \$4.2 million for the most severely affected individuals. If one takes into account quality of life issues, FAS prevention may be “cost-effective” at up to \$850,000 per child.

Mr. Harwood explained how these figures were reached. The basis for the computations were the cost estimates made for the National Institute on Alcohol Abuse and Alcoholism 5 or 6 years ago on the costs of alcoholism. Using concepts developed by the





National Institutes of Health to determine the costs of heart disease, motor vehicle accidents, and other dangers to public health, he identified the overall burden of resources lost and used in the economy to provide care for people with FAS. He estimated the number of FAS births using national estimates and data on birth rates in Arizona.

The figures that Mr. Harwood presented include both direct costs (costs to health care, social services, justice systems, etc.) and indirect costs (e.g., loss in potential productivity due to mortality, morbidity, or disability). In general, the figures are conservative, especially in relation to criminal justice costs, social service costs, and the loss of lifetime earnings. The direct cost estimate included services such as neonatal intensive care, special education services, and residential care for severe mental retardation, as well as costs for treating audiologic defects, cleft palate, and neurotube defects. It did not include costs of mental health services, criminal justice involvement, and vocational rehabilitation.

The largest percentage of the costs computed for FAS are for the residential care of children with severe mental retardation, who will need care for the rest of their lives. Special education accounts for the second largest percentage of costs. Defined medical services are the third largest category (approximately 15 to 20 percent of the total).

Mr. Harwood suggested some further areas of study to determine how best to address the cost of FAS. There is currently very little strong research on the effectiveness of specific interventions. Therefore, it is difficult to determine their cost-effectiveness. More research is needed to determine which FAS interventions are worth supporting. However, some data are available on the potential benefit of successful FAS prevention, although more research is needed in this area as well.

To determine the cost-effectiveness of a health care intervention, statisticians base their calculations on a year of life adjusted for its “quality” or “value.” Using estimates based on the reduction of quality of life from developmental disabilities, Mr. Harwood said that FAS reduces quality-of-life-years by 17 percent or 11 years. Based on that estimate, the potential savings involved in preventing one case of FAS would be \$550,000 in “quality of life” and \$300,000 in medical costs. Therefore, an intervention that cost less than \$850,000 per FAS case prevented could be considered cost-effective. The costs of preventing a case of FAS may be significant, but so are the rewards.

After Mr. Harwood’s presentation, he was asked whether the best way to address the problem of FAS was through cost sharing between multiple agencies. He answered that it was the most effective argument to use when trying to sway legislatures and service agencies.

### **FASD: Effects on the Family**

**Moderator: Julie Gelo**

Julie Gelo, the panel moderator, explained that the purpose of this panel was to allow family members with someone who has an FASD to talk about their experiences. She let panel members introduce themselves as they told their stories.



## **Teresa Kellerman**

Ms. Kellerman spoke about her adopted son, who has FAS. She was thankful that he had an early diagnosis, but at that time not much information was available on how to help her son cope with his disorder. When he was 18, she realized that her son did not have any secondary disabilities even though he had permanent brain damage, so she knows she has been doing things correctly. Ms. Kellerman has a Web site for parents of children with FAS to share effective parenting methods. She is proud of her son's success but the price paid for that success is very dear, as her whole life has revolved around keeping son healthy and safe. Her son recently left home for the first time to live in a residential care facility. While her quality of life has improved, her fears for him have increased.

## **Suzanne Lucier**

Ms. Lucier is the adoptive mother of three children with FASD. When she began to raise children with FAS, she did not know what to expect and had to learn on her own what would work for her children. All three were infants when they were adopted and had multiple problems (physical, dental, mental and emotional, eating problems, sleeping disorders, etc.). They spent all their time at home until they were at least 3 years old.

Ms. Lucier noted that children with FASD have to be treated differently than other children. She told how she found that wrapping was very helpful for one child even though a social worker said it was abusive. She home-schooled her children for a number of years until she was able to find tuition money for a private school. Even then, she had to teach the teachers how to respond to children with FAS. They would insist that a child was failing, when in fact the program was failing the child.



Her children have attention problems, cognitive deficits, and an inability to generalize. They are easily frustrated and require supervision 24 hours a day. They are also easily victimized by others and do not understand when their own behavior is socially inappropriate. She worries about her children because there is no system that really understands FAS and can care for them when she is gone. She cannot hold a job because they require so much care and supervision.

## **Ira Nelson**

Mr. Nelson spoke about raising a grandchild with FAS. His grandson has a learning disability and speech problems. Initially, they thought that he was deaf because he did not learn to speak on time. Mr. Nelson had to put aside his plans for retirement to care for his grandson. His daughter entered a treatment program but she returned to using and could not care for her

child. He had to get guardianship. It is difficult to get respite and effective schooling for his grandson and the school system does not really understand the problems a child with FAS faces.

### **Ruth Ortega**

Ms. spoke about trying to be a mother and grandmother to her 18-year-old grandson. Her grandson has been in an accident and cannot speak or see properly. He used to be a happy child but now needs to be watched all the time. He does not listen when told things and causes trouble by playing with the oven and the lights. Ms. Ortega said she was sharing her story because she needs help for him. Now that he is turning 18, she is not sure he will continue to live with her family. She also wanted to say that better services (including transportation) are needed for people with disabilities. School staff and other providers need more training about FASD.

### **David Ortega**

Mr. Ortega is Ruth Ortega's son and the father of a child with FAS. He also spoke of the need for better services for children with disabilities and better training for school staff to work with those children. Many places, including his son's school, do not have proper facilities for people with disabilities. For example, his son needs adult-sized diapers and needs to be changed but there are no facilities for changing in the high school. The school bus needs to be modified to accommodate his son as well, and he must constantly point out problems with accessibility for people with disabilities.

### **Larry Foster**

Mr. Foster was a civil rights activist in the 1970s and had studied to be a social worker. He began to have dreams of children with disabilities, so he opened a foster home in Gallup, New Mexico, for abandoned children from the reservation. His first daughter has FAE but not bad enough to qualify for special services. She has graduated from high school and a vocational institute.

Mr. Foster also has a son who was born to an alcoholic mother. This boy had alcoholic seizures 82 hours after birth and doctors initially thought he had died. He could not eat or walk properly and was malnourished. He also had problems with his heart and joints. When he grew older, he had problems in school where there was a lack of special education teachers. Today, although he is high school age he reads at a second-grade level. He enjoys computers and trains and has learned how to ride a bicycle, swim, and drive a car.

### **Katherine Young Bull**

Ms. Young Bull adopted her son from a cousin who was alcoholic. Her son is now 24 years old. When he was 19 he went to live with siblings for a while in Oklahoma but has since returned.

In his birth family (which includes nine siblings), one can see a progression in the effects of fetal alcohol exposure from the oldest, who is the least affected, to the youngest, who is most affected. Her son is in the middle. She noted that having a child with FAS is a mixed blessing, but in spite of all the problems involved he has brought a lot to her family.

### **FASD in Arizona: Where We Are and Where We Are Going**

**Moderator: Teresa Kellerman**, Director, FAS Community Resource Center

This panel included Teresa Kellerman and service providers or agency staff from different parts of Arizona.

#### **Teresa Kellerman**

Ms. Kellerman spoke about FASD in Arizona. Of 85,000 babies born in Arizona this year, 165 will have FAS and 685 will have FAE, a total of 850 with FASD. Yet Arizona Health Status and Vital Statistics Reports for 2001 show that only four cases of FAS were reported. This is a significant problem in treating FASD.

A 2001 Centers for Disease Control and Prevention study found that only 1 in 20 women who drank during pregnancy disclosed that information to their doctors after the baby was born. However, in Arizona physicians are mandated to report alcohol use by pregnant women. This may lead even fewer women to report use to their doctors. Ms. Kellerman also stated that the rate of misdiagnosis for FASD is high. She referred to a study of 48 infants born in a Houston hospital who were known to have alcoholic mothers, which found that even though 6 of the infants had signs of FAS by age 1, none of them had been diagnosed at birth.

Rates of drinking among women of childbearing age are on the rise. A SAMHSA Report for 1999 to 2000 found that 49.8 percent of women age 15 to 44 drank and 20.5 percent qualified as binge drinkers (i.e., had five or more drinks on the same occasion). In 2001, however, SAMHSA found that 53.4 percent of women in that age group drank and 23.4 percent were binge drinkers. Those percentages continue to rise, fueled in part by alcohol companies that increasingly target women with their ads.

Rates of drinking  
among women of  
childbearing age are  
on the rise.

Nor do women necessarily stop drinking when they become pregnant. Research also showed that 23.3 percent of women consumed some alcohol during the first trimester of their pregnancy and 6 percent were still consuming alcohol in the third trimester. In Arizona each year, 20,000 babies are exposed to alcohol prenatally and 10,000 are exposed to binge drinking.

Arizona has taken some steps to curb alcohol use by pregnant women. For example, the State passed a law that requires warning signs to be posted where alcohol is sold or served saying that alcohol can cause birth defects. Activists, such as Ms. Kellerman, are also involved in a number of activities to address FASD in the State.

Ms. Kellerman discussed the work being done by the FAS Community Resource Center, which has made printed and video materials available and held conferences on FASD. The Center also offers support services to families affected by FASD and airs public service announcements. Their Web site ([www.fasarizona.com](http://www.fasarizona.com)) is also extensive and popular. The Center campaigned for the signage law and now they are asking that September 9 be declared FAS Awareness Day.

### **Violet Mitchell Enos**

Ms. Enos works with the Salt River Pima-Maricopa Indian Community Department of Health and Human Services. She believes the number of children with FAS is much higher than has been identified by the State. She also said that a number of adults in the community have FASD, which causes difficulties maintaining employment or taking care of other necessary activities.

Ms. Enos stated that the Salt River Community has identified health as a priority issue, noting that diabetes and substance abuse are particular problems. The community has directed the tribal council to address the community's health needs. However, change will take time. The Department of Health and Human Services is moving toward more integrated systems of care. The department is also working to strengthen families and get community members into key roles where they can assist their community. They hope to limit the number of children who are placed out-of-home and have to grow up separated from their community. They are also trying to create a system that will support children with FASD.

### **Tony Dekker**

Dr. Dekker is a physician at the Phoenix Indian Medical Center. He works primarily with adolescents and believes that many of the children he sees may have FASD. He suggested that the increase in methamphetamine abuse in the past 6 years may in part be related to impulsivity and other problems that result from FASD. Because methamphetamine has an antidepressant effect, it may be helping adolescents calm down and feel better. Dr. Dekker suggested that more than half of the adolescents he sees who are using methamphetamine are self-medicating for some condition.

Another significant problem is teen pregnancy. Young people are often in denial about pregnancy, and zero tolerance policies drive pregnant adolescents away from schools. Better intervention is greatly needed. Across the country teen pregnancy has declined, with fewer adolescents having sexual contact and more using birth control. However, an increasing number of programs only teach abstinence, which could hinder some of the gains that have been made in this area in recent years.

## Catherine Hannen

Ms. Hannen represented the Arizona Office of Women's and Children's Health. The vision of the office is "healthy women, healthy children, healthy tomorrow." Her office has three programs that address FASD:

1. A grant to local communities to increase healthy behaviors in women of childbearing age
2. A reproductive health/family-planning program, which includes screening and education about FASD. Planning is known to improve birth outcomes, and a woman who is planning pregnancy will take better care of herself than one who has an unexpected pregnancy.
3. A screening program specifically aimed at diagnosing fetal alcohol spectrum disorders in children.

## Denise Thompson

Ms. Thompson represented the Arizona Office for Americans with Disabilities. This is a State office that does not have any specific programs for FASD. It does enforce laws that affect people with FASD. The office works on education to get State agencies to comply with disability civil rights laws, helps parents understand their rights and the rights of children with disabilities, and helps employers understand their responsibilities.

Schools are required to work on learning disabilities and help students develop an individual plan to accommodate their needs, but many schools do not do a very good job. There is protection for people with FASD under a number of civil rights laws and those laws require people with disabilities to have equal participation in State programs, school programs, and goods and services that are provided.

## Questions and Answers

A participant asked whether it is common for health professionals to misdiagnose patients. One panel member noted that it is common if all behavioral disorders are included. For example, bipolar disorder is misreported on average four times before a correct diagnosis is made. Another added that FAS diagnoses are often missed and that misdiagnosis may be the rule rather than the exception. An additional problem is that once a correct diagnosis is made it does not ensure that a person has access to care.

## Local Diagnostic Clinics and Local Resources

**Sarah Iden, MPH**, Department of Pediatrics, University of Arizona  
**Teresa Kellerman**

Ms. Iden noted that a handout included in attendees' packets provided addresses and phone numbers for genetics clinics that can diagnosis FAS. She pointed out that she was going to discuss FAS specifically because FASD is not a diagnostic term. FAS is a diagnosis generally made by clinical geneticists and dysmorphologists (a specific type of clinical geneticist focused

on recognizing differences in clinical features). However, primary care providers and other medical specialists can make the diagnosis if they have training.

FAS is a clinical diagnosis based on set criteria that include facial characteristics, pre- and postnatal growth retardation, and evidence of central nervous system dysfunction. There must also be a history of prenatal alcohol consumption. The amount, timing, and duration of prenatal exposure to alcohol significantly affects the disorder.

An FAS evaluation begins with the doctor taking a complete history that looks closely at the pregnancy to determine:

- The amount, timing, and duration of alcohol exposure, if known
- Other drug exposures
- Complications in pregnancy
- Birth weight, length, and head circumference of the newborn

A medical and developmental history is also taken that focuses on learning and behavior issues. Then the child is given a thorough physical exam and other possible diagnoses are considered. The exam assesses specific features such as the distance between the child's eyes and the child's growth and development. After the exam, the clinician will discuss his or her impressions with family. If the diagnosis is FAS, the clinician will refer the family to other specialists and local and national support organizations.

FAS can be diagnosed throughout a person's lifetime but different criteria are more pertinent at different ages. For example, the facial features are most prominent in young children, and growth retardation is ideally noted during the prenatal period and at birth. It can be difficult to establish an accurate history of prenatal alcohol exposure. Neonatal toxicology screens do not detect alcohol. If there is a history of alcohol use, it is often noted in the mother's records but not the child's. It is extremely important to be nonjudgmental when obtaining exposure history.

Ms. Iden also reviewed some of the places in Arizona where an FAS diagnosis can be made and the expected costs and insurance coverage for an assessment.

## Closing

### Candace Shelton

Ms. Shelton closed the meeting by thanking participants and staff who worked to put it together. She stressed the importance of keeping this issue at the forefront of public consciousness by talking to people about FASD and advocating for prevention and treatment.